

InTBIR Data Management Work Group

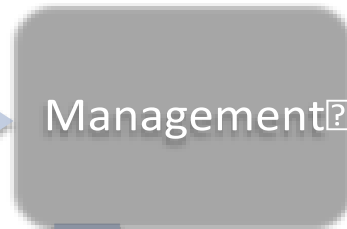
Team:

Tony Fabio (co-chair), Lindsay Wilson (co-chair), Jeffrey Grethe, Mary Vassar, Matthew McAuliffe, Michael Jarrett, Sirimon O'Charoen, Pradeep George, Tania Khasanova, Vibeke Brinke, Guido Bertolini, Ferath Kherif, Mona Hicks

Data to Knowledge Pipeline



- Submission
- Access
- Data Use Agreements
- Informed Consent/Data Protection



- Data Dictionary
- Curation
- Quality Control
- Platforms/Archives



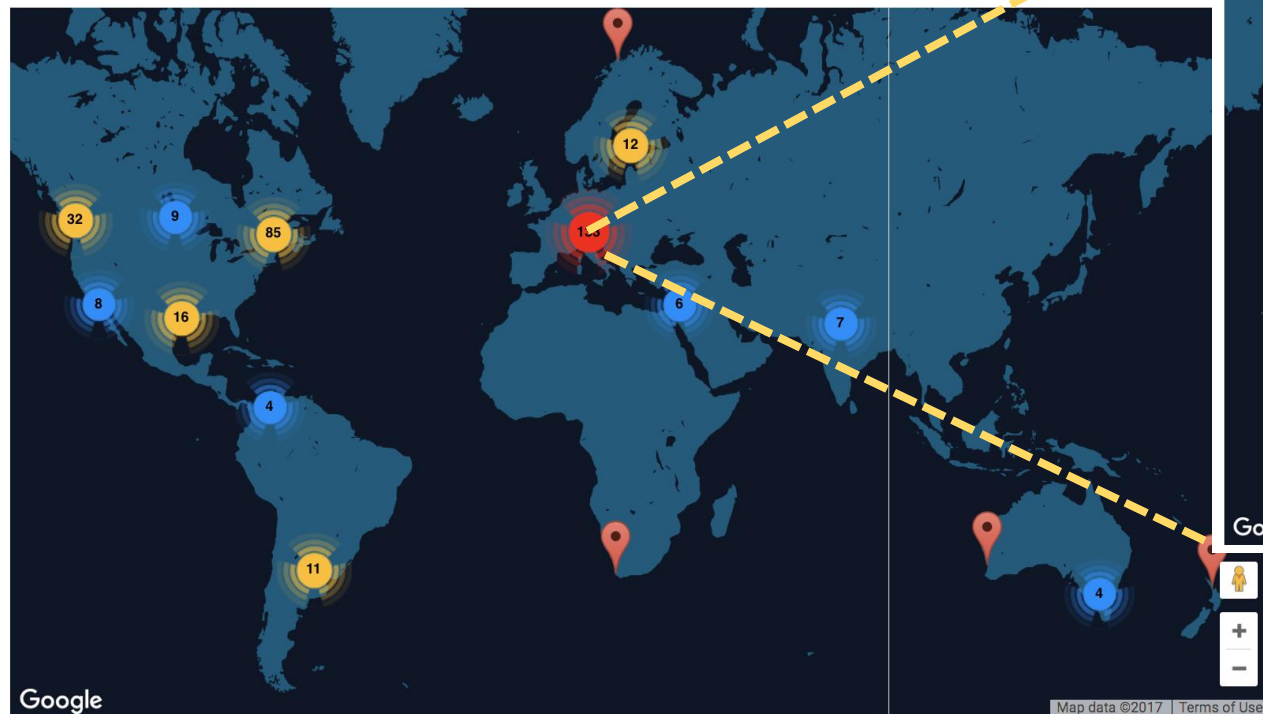
- Statistics and Graphics Tools
- Questions/Idea Board



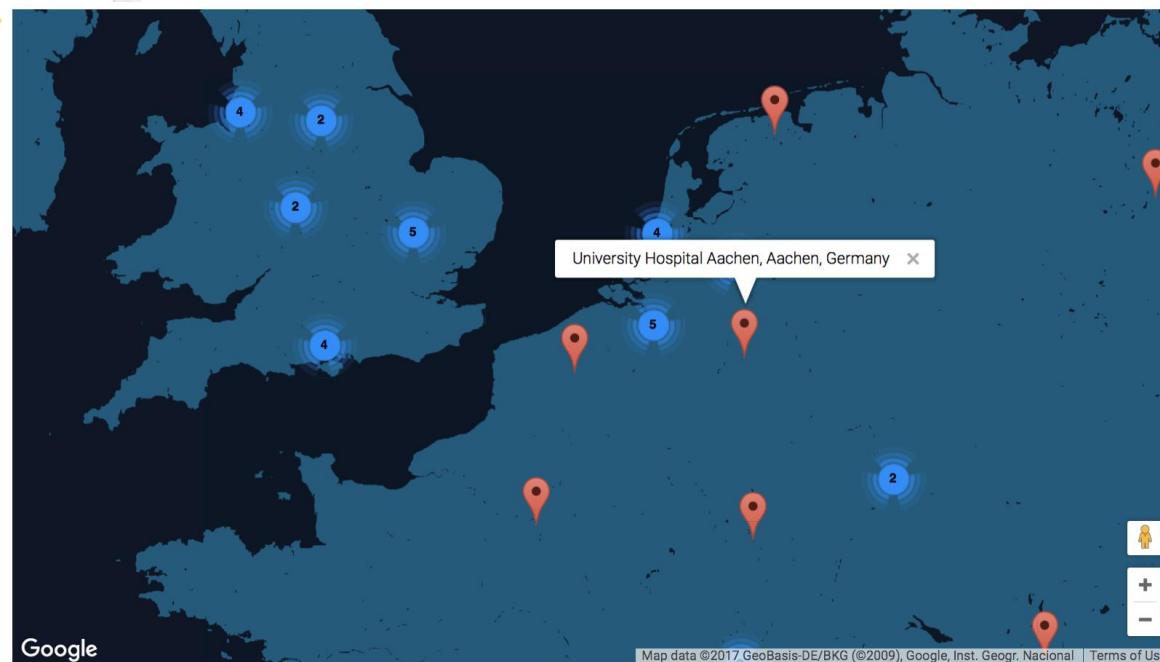
Projects & Interactive Clinical Sites Map

You are here: [Home](#) > [Projects](#)

<input checked="" type="checkbox"/> All (331)	Website <input checked="" type="checkbox"/> 5P (9)	Website <input checked="" type="checkbox"/> Creactive (72)	Website <input checked="" type="checkbox"/> LABIC (16)
Website <input checked="" type="checkbox"/> ADAPT (49)	Website <input checked="" type="checkbox"/> 15-Yr Study (1)	Website <input checked="" type="checkbox"/> CENTER-TBI (68)	Website <input checked="" type="checkbox"/> CENTER-TBI Affiliate (8)
Website <input checked="" type="checkbox"/> TRACK-TBI (20)	Website <input checked="" type="checkbox"/> TEAM-TBI (1)	Website <input checked="" type="checkbox"/> Ped-CDE (7)	Website <input checked="" type="checkbox"/> Neurocare (1)
Website <input checked="" type="checkbox"/> Hemotion (19)	Website <input checked="" type="checkbox"/> Safe to Play (1)	Website <input checked="" type="checkbox"/> PlayGame (1)	Website <input checked="" type="checkbox"/> TBI-Prognosis (17)
Website <input checked="" type="checkbox"/> CTRC (41)			



Information on Participating Sites



University Hospital Aachen, Aachen, Germany

The FAIR Principles

SCIENTIFIC DATA

OPEN **Comment:** The FAIR Guiding Principles for scientific data management and stewardship

SUBJECT CATEGORIES

- » Research data
- » Publication characteristics

Open
data
is about
MORE
THAN
DISCLOSURE
it must be
Fair

- Findable
- Accessible
- Interoperable
- Reusable



<http://www.nature.com/sdata/> nature publishing group 

First steps in enhancing collaboration around data is to ensure that it is findable and accessible...

- **Findable:** A core aspect of an open data ecosystem - facilitate access to a collection of diverse research resources
- **Accessible:** Assist users by directing them to available resources for that researcher including information on policies and procedures for access
- **Interoperable:** Provide unified views of certain data and information across resources
- **Reusable:** Supports community standards and develops standard representations for resources
- **Attribution and Recognition:** Initiatives to unambiguously cite resources and data

Discover and access

Collaboration and sharing of



Marketplace

Find brain and mental health projects and research data.

Explore

Marketplace

Categories

All

Apps

Data

Create Packages

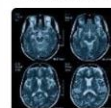
Publisher

OpenWorm Cell Lineage



A PDF containing a diagram of the cell lineage of the c. elegans.

TRACK-TBI - TED Idea Board



A Trello based board to manage and discuss ideas revolving the TRACK-TBI data.

TRACK-TBI in tranSMART



TRACK-TBI is built from the foundational NINDS-funded TRACK-TBI Pilot study, which collected clinical data from 3 sites and 600 subjects.

NNDC - CCR



The NNDC CCR Data Set includes data on 1,500+ patients presenting with a depressive episode from 18 participating NNDC Centers of Excellence

TRACK TBI PILOT in tranSMART



TRACK-TBI is built from the foundational NINDS-funded TRACK-TBI Pilot study, which collected clinical data from 3 sites and 600 subjects.

CENTER-TBI in tranSMART



Collaborative European NeuroTrauma Effectiveness Research in TBI (CENTER-TBI)

NNDC - rTMS

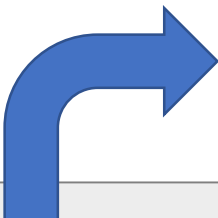



The rTMS Data Set includes data on 60+ patients presenting with a depressive episode from 9 participating NNDC Centers of Excellence.

Contact us!

Overview of Datasets

Login provides additional detail





TRACKTBI-PILOT

[+ Request Access](#)

Restricted

Published
Nov 29, 2016

Managed by
Erik Montes

Contact

Terms & Conditions

OverviewDiscussionsUsersProject BoardMessages

Overview

Transforming Research and Clinical Knowledge in TBI Pilot (TRACK-TBI):
The global aim of this proposal is to test and refine Common Data Elements (CDEs), neuroimaging standards, and best practices for genetics and proteomics in Traumatic Brain Injury (TBI) studies. Testing and validating of TBI-CDEs will be performed in a multi-center prospective observational study with 3 TBI Centers (San Francisco General Hospital (SFGH)

Read More

Access Requirements

- Users should be a qualified researcher who is accessing the data to test hypotheses and/or answer questions related to brain health.
- Willing to share their research with others through the portal to accelerate knowledge about brain/mental health.

Meta Data

Number of Subjects	599
Species	Human

Please [sign in](#) or [sign up](#) to view additional meta data.

Keywords

TRACK-TBI PilotTransmart

10 people use this app

Recent discussions

4 months ago Erik Montes commented on "Greetings"

8 months ago Erik Montes commented on "Measuring PTSD in 5-10 year olds"

1 year ago Erik Montes posted "When will new data be available? "

View Posts

TRACKTBI-PILOT

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AccessGranted

Overview

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Recent discussions

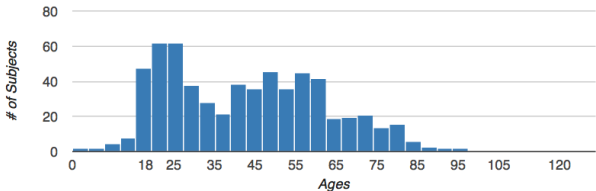
4 months ago Erik Montes commented on "Greetings"

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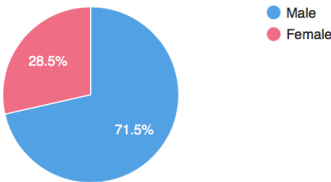
1 year ago Erik Montes posted "When will new data be available? "

View Posts

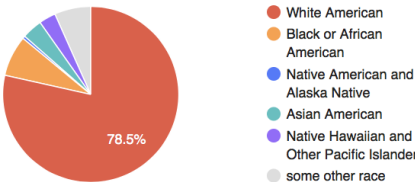
Subjects by Age




Subjects by Sex



Subjects by Race





Play Game Trial

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Sep 25, 2017

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The Play Game Trial is part of the Childhood Traumatic Brain Injury Research Program, Alberta Children's Hospital Research Institute, University of Calgary.


The trial is registered at clinicaltrials.gov and the protocol has been published in medical journal "Trials" <http://www.trialsjournal.com/content/15/1/271>

The trial is funded by Canadian Institutes of Health Research. The trial leads are Dr Karen M Barlow and Dr. Deborah Dewey.

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Meta Data

Species	Human
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ADAPT

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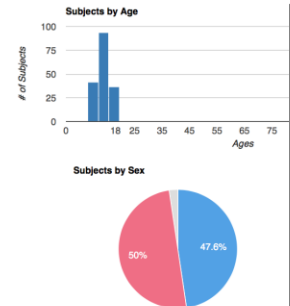
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Approaches and Designs designed to evaluate traumatic brain injury

Meta Data

Species	Human
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TEAM TBI

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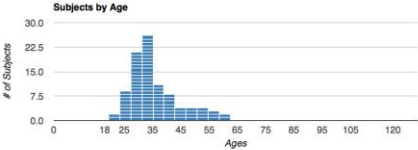
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TEAM TBI is a federally-funded research study at the University of Pittsburgh that investigates the complexity of brain injury, and how targeted interventional strategies may improve outcome and function.

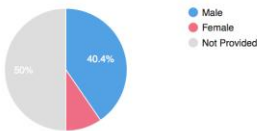
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Meta Data

Subjects by Age



Subjects by Sex





InTBIR Studies

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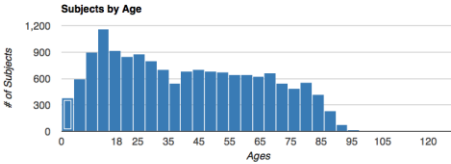
InTBIR is a cooperative effort of the European Commission (EC), the Canadian Institutes of Health Research (CIHR) and the National Institutes of Health (NIH) to coordinate and leverage clinical research activities on traumatic brain injury (TBI) research. InTBIR's goal is to improve health care and lessen the global burden of TBI by 2020 through the discovery of causal relationships between treatments and clinically meaningful outcomes. InTBIR seeks to encourage well-designed, hypothesis-driven studies that include the collection of high quality data followed by rigorous statistical analysis.

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Meta Data

Number of Subjects	15,162
Primary diagnosis	TBI
Species	Human

Subjects by Age



Subjects by Sex

